Destruction of data prompts calls for Swedish agency to investigate research misconduct

Caroline White *London*

Leading academics are pressing the Swedish government to set up an independent agency to investigate issues relating to scientific research misconduct after a long running dispute resulted in the destruction of years of patient data.

The man at the centre of the dispute is Christopher Gillberg, professor of child and adolescent psychiatry at the University of Gothenburg, Sweden, and St George's Hospital, London, and a world expert on attention-deficit/hyperactivity disorder (ADHD) and autism.

In May, years of data relating to Professor Gillberg's research were destroyed by two of his collaborators, associate professors Carina Gillberg and Peder Rasmussen, and university administrator Kerstin Lamberg, in a bid to protect patient confidentiality.

Vice chancellor of Gothenburg University Professor Gunnar Svedberg says that he received a letter the following day from the three, explaining what they had done, and why. But it is illegal in Sweden to destroy archived material collected with public monies, and the university has commenced legal action against them.

The destruction of the data followed a court order given to Eva Kärfve, associate professor of sociology at the University of Lund, granting her access to Professor Gillberg's research files.

She claims to have found various numerical "inconsistencies" in his long term, published research.

Gothenburg University rejected her claims. A subsequent investigation by the regional ethics committee did the same. But Professor Kärfve sought legal redress so that she could see for herself. "Gillberg's work [on ADHD-DAMP (deficits in attention, motor control, and perception)] has had an enormous impact on Swedish social policy," she said.

In emails to the *BMJ* Professor Gillberg stated that Professor Kärfve was one of four people who had "made false allegations against me for years, allegations that have been refuted by all relevant authorities after extensive investigations."

The "inconsistencies" were "non-existent," he wrote, adding that members of the church of Scientology had been running a lengthy campaign to discredit his research. Professor Kärfve's views reflected those espoused by certain Scientologists, he said.

Professor Kärfve admitted attending a Scientology meeting on ADHD in Munich, but for research purposes only, she says. She denies any involvement in the group.

Elias Eriksson, professor of pharmacology at Gothenburg University, said the destroyed files contained "very, very sensitive information." Many study participants begged for it to be kept confidential, and "hundreds of medical researchers" believed that to hand it over "would violate the entire ethical basis for medical research in Sweden."

Both Professor Svedberg and Professor Gillberg told the *BMJ* that they did not know that the data were going to be destroyed.

Professor Gillberg wrote: "I was completely unaware of the process… I am, of course, devastated by the fact that the data had to be destroyed."

Professor Svedberg contends that the safeguards for patient confidentiality "collided" with the legal requirement for total transparency in publicly funded activities. "Medical scientists say this is very dangerous for medicine," he said, adding that the university had now turned to national educational and research bodies for help.

The deputy director general of the Swedish Research Council, Professor Madeleine Leijonhufvud, said that "the idea of a scientist having to destroy data is very bad, and we have to do something about it." But she was optimistic that the council's appeal to the government to establish an independent agency on scientific misconduct would be accepted. □

US to introduce new rules on air pollution

Janice Hopkins Tanne *New York*

The US Environmental Protection Agency is finally introducing the first air quality standard governing fine air particles to make breathing safer for Americans, seven years after it first proposed the changes.

More than 99 million people—a third of the US population—live in areas with unhealthy levels of 2.5 micron particles in the air, says the agency. The smaller the particles, the easier it is for them to get deep into the lungs. The particles come from vehicle exhausts, industrial sources such as factories and coal burning electrical power plants, locomotives, diesel powered farm and construction equipment, diesel powered ferries and tugboats, and domestic sources such as wood burning stoves and fireplaces.

AP PHOTO/DAVID ZALUBOWSKI

Particulate air pollution causes 100 000 US hospital admissions a year

The agency originally proposed the new standards in 1997, but they were challenged and finally upheld by the Supreme Court in 2001. Industry groups had wanted lower standards; environmental groups wanted higher ones. The new standards are exactly the ones proposed in 1997.

In late June, the agency notified states and tribes—that is, those living in large reservations—that 243 counties did not meet the standards for particles smaller than 2.5 microns. The counties are located in eastern and midwestern states and in California.

However, state governors said that only 141 counties were not in compliance with the standards. The federal agency and the states will discuss the issue, and in November the agency will produce a final list of states with counties that are not in compliance. By 2008 the states must have developed plans for meeting the air quality standard, and they must comply with the standards by 2010 to 2015.

Even partial attainment of goals by 2010 would prevent at least 15 000 premature deaths a year, mainly from heart and lung diseases or complications of these disorders. Agency spokesperson John Millett told the *BMJ* that particulate matter air pollution caused 75 000 cases of chronic bronchitis each year, 10 000 hospital admissions for respiratory and cardiovascular diseases, 20 000 cases of acute bronchitis, hundreds of thousands of cases of aggravated asthma, and 3.1 million days of missed work.

Corrective plans will depend on the source of the particulate matter. Mr Millett said that states might, for example, curb industrial growth, electrify highway truck stops (so that drivers do not need to keep their engines running for heat or air conditioning), or make public transport free on days with high pollution levels to discourage use of private cars.

States will be penalised if they do not submit plans to meet the standard or do not implement them. Penalties might include loss of federal funding for highways. □